

Dementia and financial incapacity: a caregiver study

Olivia DaDalt, Arielle Burstein, Birgit Kramer, Lisa A. D'Ambrosio and Joseph F. Coughlin

Olivia DaDalt is a Research Assistant at AgeLab, Massachusetts Institute of Technology, Cambridge, Massachusetts, USA.

Arielle Burstein is based at the Milken Institute, Santa Monica, California, USA.

Birgit Kramer is a PhD Student at the Network Aging Research, University of Heidelberg, Heidelberg, Germany.

Lisa A. D'Ambrosio is a Research Associate at the Massachusetts Institute of Technology, Cambridge, Massachusetts, USA.

Joseph F. Coughlin is based at the Massachusetts Institute of Technology, Cambridge, Massachusetts, USA.

Abstract

Purpose – *The purpose of this paper is to identify strategies that caregivers of people with dementia use for financial and estate planning and what advice they would give to others in their position.*

Design/methodology/approach – *Data were gathered via in-depth in-person interviews with 34 caregivers of individuals with dementia. Participants were asked questions about: how they financed care; the resources and people they used to help manage care and finances; and advice they would give to other caregivers.*

Findings – *Caregivers wished that they had done more in-depth planning regarding dementia care and financial arrangements. Participants also wished they had saved more money for care expenses or a “nest-egg.” Participants had mixed feelings about the usefulness and trustworthiness of financial advisors, but those who had elder care lawyers recommended them highly.*

Research limitations/implications – *It would be beneficial to reproduce this study with a larger, gender-balanced sample with a wider variety of socio-economic backgrounds.*

Social implications – *The advice and insight provided in this paper are useful both to dementia caregivers, who can learn from the experiences of those interviewed, and to industry professionals such as financial advisors and elder care lawyers, who may recognize from these interviews the areas in which caregivers need assistance and the services they can provide to help them navigate this disease.*

Originality/value – *This paper provides insights from actual caregivers about their experiences dealing with the financial aspect of dementia, an aspect of the disease that is not widely discussed.*

Keywords *Dementia, Caregiving, Finance, Alzheimer's, Estate planning, Financial advisors*

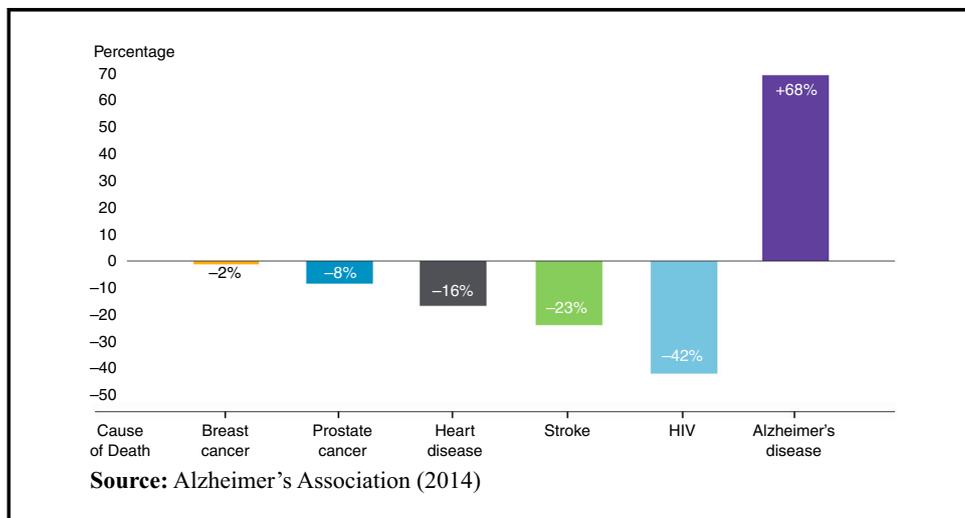
Paper type *Research paper*

Introduction

Although heart disease, cancer, and diabetes are often cited as the most dangerous and deadly diseases of our time, Alzheimer's disease (AD) may be the most heartbreaking. AD is a progressive neurological disease that affects an individual's memory and cognitive function. It is the most common form of dementia. Symptoms often manifest first as forgetfulness and loss of short-term memory, followed by increasing cognitive decline as the disease progresses, until finally those with the disease are unable to perform even the simplest tasks of daily living without assistance and/or careful surveillance (Karttunen *et al.*, 2011; Förstl and Kurz, 1999).

Over the past ten years, rates of major causes of death in the USA (e.g. heart disease, HIV, stroke) have all been on the decline; only AD rates continue to rise (see Figure 1). Diagnoses of AD are rapidly growing in the USA; currently, an estimated 5.2 million Americans struggle with AD. That number is expected to rise 40 percent to 7.1 million by 2025 and will triple to as many as 16 million by the year 2050 (Alzheimer's Association, 2014). This surge in the prevalence of the disease will mean not only an increase in patients with AD, but also in caregivers. A generation of baby boomers faces the task of caring for elderly parents, only to need care themselves a few years later from their own children.

Figure 1 Percent changes in lead causes of death in the USA, 2000-2010



Caregiving comes with many costs: in 2013, 15.5 million Americans provided 17.7 billion hours of unpaid care to dementia patients valued at over \$220 billion (Alzheimer's Association, 2014). Furthermore, caregiving is an expensive "occupation." A large majority of caregivers (74 percent) held a paid position while also providing care to their loved one, and 69 percent reported having to re-arrange their schedules at work, come in late, or take days off at a time in order to provide care (National Alliance for Caregiving and AARP, 2009). Such disruptions in caregivers' work schedules can affect their financial fortunes; according to a MetLife study, caregiving cost an estimated total average of \$324,044 in lost wages, social security benefits, and pensions for women and \$283,716 for men (MetLife, 2011). Caregivers also report spending 10 percent or more of their annual net income on caregiving expenses, which in 2007 amounted to about \$5,531 per year (National Alliance for Caregiving and Evercare, 2007). These expenses add up: over a quarter of caregivers reported experiencing a moderate to high degree of personal financial difficulty due to caregiving (National Alliance for Caregiving and AARP, 2009).

Background

One symptom of AD that can significantly complicate the task of the caregiver is the breakdown of the care recipient's financial skills and the loss of the ability to handle money and manage basic transactions. This can result in money mismanagement and financial choices, which may, in turn, put patients and their families at risk. Difficulties with finances can begin early in the disease progression and may sometimes precede the official diagnosis of AD (Triebel and Marson, 2012; Widera *et al.*, 2011; Marson, 2013). Early signs of a decline in financial skills can include small problems, such as forgetting to pay bills or misplacing financial documents, but they can also include making rash decisions concerning finances, such as investing in get-rich-quick schemes and spending money excessively and unwisely. Individuals with AD are more vulnerable to financial fraud (Gamble *et al.*, 2014). As the disease progresses, people with AD ultimately lose all financial capacity and become wholly unable to manage their own finances (Widera *et al.*, 2011). This is an issue that has implications beyond merely the care recipient; it affects anyone whose money or assets may be linked to that person's, such as a spouse's retirement savings, a trust fund managed on behalf of a grandchild, or even a business partner's earnings.

The stress of dealing with a loved one's financial incapacity, in addition to other worsening AD symptoms, can weigh heavily on caregivers and family members. Ideally, individuals and families make arrangements to put these affairs in order early on, while the individual has the financial and cognitive capacity to participate fully in these discussions. Failure to make these kinds of

arrangements could lead to significant financial and legal challenges later. Professionals, such as financial planners, elder care attorneys, and geriatric care managers, are often in a position to offer significant help to families dealing with the intricacies of financial planning and AD. The objective of this paper was to identify financial planning or management strategies among families caring for someone with AD.

Methods

Sample

The sample consisted of 34 individuals in the metro-Boston area who reported that they provided any level of care for a loved one with a diagnosis of AD or another form of dementia; nearly all (94 percent) were the primary caregivers. Caregivers were recruited by a professional focus group facility and then screened by the research team. The sample included six male caregivers and 28 female caregivers between the ages of 43 and 76, with a mean age of 59.3. Caregivers' reported annual household income ranged from \$25,000 or less to over \$150,000, with a median income category of \$50,000-\$74,999. Most of the caregivers in the sample were spouses of the care recipient (41 percent), although there were also a number of adult children and grandchildren (32 percent). Three of the participants were friends or neighbors (8 percent), and the remainder (19 percent) were other relatives such as siblings, nieces, nephews, daughters-in-law, or cousins. The care recipients included 19 females and 15 males, ranging from 55 to 94 years old, with a mean age of 77.3. A majority of caregivers reported that their loved ones were in the moderate stage of dementia (62 percent); 17.5 percent said they cared for someone in the mild stage, and 20.5 percent reported caring for someone in the severe stage. All participants were caring for loved ones who lived in the community, either with others (76.5 percent) or independently (23.5 percent); none lived in a nursing home or other type of professional care facility, which was part of the inclusion criteria of this study.

Data collection

Caregivers took part in an in-person interview and answered a number of open-ended questions relating to how they manage their loved ones' finances. The discussion included how caregivers paid for or financed their loved ones' living expenses and health care, what they thought they could have done differently in caring financially for their loved ones, the use of professional advisors, and what they would recommend to others in their situations regarding financial caregiving. These questions were part of a longer interview that also examined caregivers' awareness and acceptance of a number of new caregiving technologies. This portion of the interview was a replication of a German study on the topic (Kramer, 2014), but the financial caregiving items were unique to this sample. Interviews took place either in the caregiver's home or at the MIT AgeLab. The interviews were audio recorded and transcribed, and the authors cross-checked the audio recording against the transcript of each interview. The authors read through the transcripts to identify emergent themes in participants' responses.

Results

Dealing with financial incapacity

The interviews revealed much about how caregivers managed the daily issues surrounding finances and care. Caregivers varied in the amount of time and involvement they dedicated to dealing with finances, with some participants doing as little as simply paying bills online or by telephone for their loved ones. Others had more responsibilities, including setting up trusts and managing all of their loved one's investments. Furthermore, participants also varied in how burdened they felt in assuming the role of financial caregiver. Those who had long been managing their loved ones' finances felt little change in their financial duties. To others, however, the shift was monumental and they felt themselves burdened by a whole host of new financial responsibilities that they struggled to manage. "I mean, I looked at all this paperwork and I thought where do I begin? I don't know anything about this. I don't know what they mean," recounted one female spouse, age 62. "It freaked me out almost as much as the disease did.

Because I thought, my God, we're going to lose everything," she said, highlighting the stress and confusion she felt in taking on financial responsibilities. Those who are forced to assume new financial duties must undergo a sort of "role expansion" that can be stressful and put added pressure on their already demanding lives.

Advice to other caregivers

Several themes emerged in participants' responses to questions about what they would do differently in terms of financial planning for their loved one's AD or what advice they would give others in their same situation. Caregivers touched on ideas of better planning in terms of spending specifically for their loved one's care and in terms of their own financial longevity. Participants' answers were grouped into four main categories: plan more; save more; purchase health care coverage; and take advantage of resources.

Theme 1: do more planning. Over a third of participants (38.2 percent) said they would have "planned more." This category included responses such as making more detailed or different arrangements in terms of property, financial accounts, health insurance, and retirement plans, such as changes in the ownership of a house and the establishment of trusts and pensions. One female spouse, age 68, noted that if she could do something differently, she would have made sure that "everything would be put in my name or I would set up a trust differently, that it would be a more sheltered trust, where things would be – I wouldn't be so exposed to financial responsibility." Another female spouse, age 62, said that she "would have convinced [her] husband not to take the pension plan that he took, where his pension dies with him. He knows that's a mistake he made. But there was no one giving him any other advice." Many participants wished they had reviewed their options more thoroughly and made allowances for the poor health or complicated situations of one or both spouses.

Participants also noted how important communication with their loved ones was to the planning process, particularly before the disease progressed to the point that the individual was unable to make decisions for him or herself. "The most important thing is not to wait to have this conversation [about financial planning]. It's [of] supreme importance to not wait until somebody is incapacitated [...] because you don't want anybody else making those decisions for you. And that's the bottom line," said one caregiver daughter, age 51. The participant's assertion highlights the concern that unless financial issues are discussed with the individual and settled early, they risk remaining open and being decided by third parties, such as another family member or a policy or legal guideline, leaving caregivers powerless and the changing the ultimate outcome to one the care recipient would not have wanted.

Finally, participants mentioned that they would have simply been more proactive and conscientious about planning in general. One caregiver daughter, age 51, said: "I would have had more of an open dialogue on the importance of having everything in writing, and have everything documented as far as, like, what you have coming in, what you have going out, life insurance. Have all documents in one place. That is very important." Caregivers thus recognize the importance of documenting the financial preferences and wishes of their loved ones. They also value simply having general records of all assets and income to make planning and organizing finances clearer and easier.

Theme 2: save more. The second theme that emerged in conversations with caregivers was that they would have "saved more" had they known that they would become caregivers. Nearly a third of participants (32.3 percent) said that they would have saved more whether that meant putting more money aside "for more of a cushion," as one participant said, or simply spending less in the years leading up to the care recipient's diagnosis. Overall, participants seemed to agree that saving more and spending less would have been beneficial considering their current caregiver status. One female spouse, age 69, explained that financial planning and saving extra was especially important because dementia-related costs often mount quickly and support from health care or insurance may be lacking. "I think that many people don't know what the costs that are facing them really are, whether it comes to Alzheimer's [or] dementia care in a facility. I think there are many people who erroneously think that Medicare covers, you know, a lot, and it does

not,” she said. Many participants did not seem to plan for any complications in their own or their loved one’s old age, and instead they simply budgeted for an uneventful retirement. Looking back, many families reported that they wished they had “planned for the unexpected,” as multiple participants said, instead of simply hoping (and planning) for the best.

Theme 3: purchase health care coverage. A third theme revolved around having the right health care coverage to pay for care expenses. One fifth of caregivers (20.5 percent) mentioned Medicare and Medigap insurance and the importance of good health coverage, which for participants meant coverage that would finance care throughout the course of the disease. Over 70 percent of these participants (71.4 percent; 14.7 percent of the total sample) also raised the issue of long-term care insurance, and how they would have liked to have gotten it earlier. One female spouse, age 67, said: “I think I would have gotten my long-term care insurance when we were younger, and it would have been less expensive. Because we didn’t get it until we were in our late fifties, early sixties.”

Purchasing long-term care insurance can be a complicated decision for some families. Although it is generally less expensive when one is younger, before health problems and other premium-increasing conditions set in, buying it sooner also means that one must pay over a longer period of time. Other research has shown that people who do not have a high perceived risk of poor health in the future are less likely to purchase long-term care insurance (Brown *et al.*, 2012; Finkelstein and McGarry, 2006). People may find it difficult to imagine themselves as old and vulnerable, and thus see no need to invest in long-term care insurance for themselves. Indeed, one female caregiver, age 66, explained that it was important for people to “just make sure that they’ve got the right health plan, and they’ve got the finances to back themselves up,” but she also conceded that “you know, you’re young, you’re foolish. You don’t ever think you’ll get to that kind of stage, that you have to worry about things like that.” While the decision to purchase long-term care insurance may differ from individual to individual and family to family, caregivers in this sample generally considered it beneficial and wished they had purchased it sooner.

Theme 4: utilize available resources. Finally, caregivers mentioned the importance of becoming familiar with and taking advantage of resources available on dementia (11.7 percent). These participants felt it was crucial that caregivers be proactive in finding available services and programs to help with anything from home care to health and treatment. One female caregiver, age 61, urged others to “make sure that you get all the services that you can get. You know, whatever your insurance will cover.” Other caregivers suggested taking advantage of resources like local transportation services such as paratransit, delivery services such as Meals-on-Wheels, and local or community day care services or support groups provided by senior centers or local Alzheimer’s Association chapters.

Caregivers and paying for professional advice

Because families with a loved one with AD may have to navigate complicated financial matters, professionals knowledgeable about such issues could be of invaluable help. The interviews included questions about professional financial advisors as well as elder care attorneys and other professional sources of advice caregivers used.

Views about financial advisors. Participants’ reactions to what they thought of financial advisors, both generally and as a possible resource for caregiving, were mixed. While some viewed financial advisors as helpful for managing finances and a potential resource for caregiving, others saw them as untrustworthy and not useful around caregiving.

Of the participants interviewed, 13 caregivers (38.2 percent) used a financial advisor. We asked the 21 participants who did not have a financial advisor whether they would like to have one, and the majority (90 percent) said that they would not. The main explanations offered were that financial advisors were expensive and that participants did not feel that financial advisors could do more to manage their money successfully than they themselves had done. One female caregiver, age 69, summed it up as “it’s a considerable amount of money just to go to a financial advisor. I mean, I know exactly how much money we have, but I don’t know if a financial advisor would necessarily be able to [...] make it go any further.”

Participants also expressed some trust issues regarding financial advisors. When asked whether or not financial advisors could be trusted or not, one participant said “no, they swindle [...] I’d rather get a little bit less and feel more safe and secure that my money’s there. Rather than lose my whole retirement money, you know.” Only one participant’s advice to other caregivers included getting a financial advisor.

Interestingly, however, participants who did trust financial advisors were those who described themselves as having longstanding, close, interpersonal relationships with their financial advisors. One male caregiver, age 66, explained that he trusted his advisor because “I did well in business for the years with him.” A female caregiver, age 60, noted that she trusted the advisors she worked with because they had been so supportive and helpful over the years that they had become like family: “It’s just that we’ve had them for a long time, they’ve always maintained our investments and increased them, and they’ve become a family financial advisor because my sister-in-law, even before us, used them. That’s how I found out about them. I called them in when my father died, and they came – they traveled from Boston to New Jersey to meet with my mom and help me to get her finances in order. Then, we used them and my son, who’s an attorney, he’s now using them.” Clearly the advisors’ long-term commitment and loyalty to this client, in addition to their competent financial management earned them not only her trust and confidence, but also ensured future business by securing a spot as the financial advisors to other members of her family.

Roles for financial advisors. Participants were also asked whether or not they thought financial advisors could be a resource in caregiving for someone with dementia. The responses suggested that many caregivers do not imagine support with caregiving to be part of the average financial advisor’s role. Nearly half (47.1 percent) said financial advisors would not be a useful resource in dementia care, whereas over a third of the participants (38.2 percent) said that they could be helpful. The remaining participants (14.7 percent) said may be or that they were not sure if the advisor could be useful.

Participants did, however, have some ideas about how a financial advisor could be useful to those dealing with dementia. The nature of the help fell into three main categories: help with financial management; help with health care; and help with information about available resources and services.

Help with budgeting. Participants most frequently mentioned that they felt financial advisors could help them with financial management – helping them to organize their affairs and to budget. Nearly half (47.1 percent) of participants mentioned that they would want financial advisors to help them “make the money last longer” or “budget for unforeseen expenses.” One female adult child caregiver, age 56, expressed the wish that a financial advisor would “walk me step-by-step. You need to do this by this amount of time, you need to do that, this.” Another female spouse, age 55, said she would want someone to “make sure I wouldn’t be making any mistakes as far as what I would do with funds at certain times of the disease.” These comments suggest that caregivers are looking for guidance or a sort of road map for how to budget their expenses and what they should spend when.

Within this group, a few participants also said they could use financial advisors’ help with basic estate planning, such as with wills and power of attorney. One daughter-in-law caregiver, age 51, said “they could help you put your affairs in order and just see what you have, from when you make up your will, to decide who gets what. What proportion is going to go here? What proportion is going to go there?” In short, some caregivers wished for financial advisors to serve as managers: people who could see the larger picture over time and offer advice about the ordering and allocations of financial matters.

Help with health care. The second area in which participants thought that financial advisors could be helpful was in terms of planning for health care; 20.5 percent of participants mentioned having a financial advisor help them plan for and/or finance their loved one’s care. One female spouse, age 71, said the only reason she was getting a financial advisor was to help her plan for and afford long-term care. Another female spouse, age 64, said that she would want a financial advisor to “make it possible to be able to afford nursing homes.” Thus, for some caregivers, financial

advisors could be of the greatest use to address their fears and concerns about being able to afford the health care costs that accompany AD – from providing in-home care to placement in a skilled nursing facility – in order to provide their loved one with the level and quality of care he or she required.

Help with information. Finally, several participants (8.8 percent) said that advisors could be helpful in informing them about resources and programs available for caregivers of people with dementia. One female caregiver, age 63, said she would want a financial advisor to “network with me about programs,” such as financial planning, health, “anything.” This suggests that some caregivers may be looking for financial advisors to act as a kind of concierge, able to direct them to the most helpful resources and services to help them cope with the various demands and stresses of caring for a loved one with AD.

Views about elder care attorneys. Participants were also asked about elder care attorneys as a source for professional advice. Contrary to some caregivers’ reservations about financial advisors, participants were very enthusiastic about elder care lawyers and the help they could and did provide. Although elder care attorneys did not figure prominently in responses to questions about what caregivers would do differently or what advice they would give to others, they were mentioned more often when participants talked about how they successfully managed and coordinated their loved one’s care. In total, nearly a quarter of participants (23.5 percent) mentioned using and an elder care lawyer, and nearly all of them suggested that they were a helpful resource in planning for their loved one’s care.

Participants were pleased and impressed with elder care lawyers’ knowledge of complex legal processes relevant for an individual and family dealing with AD, including drawing up powers of attorney forms, transferring ownership of a home and other assets to try to protect or retain them for the family, and preparing wills and do-not-resuscitate orders. When asked why she felt confident in her elder care lawyer, one caregiver, age 56, explained that it was “because she knows the law and she knows what I need to know that I don’t know.” Another female participant, age 55, an adult child caregiver, recounted that her elder care attorney “basically walked me down the steps that we needed to do. That was the best money that we ever spent, because I didn’t know anything.”

Participants also mentioned that elder care attorneys were instrumental in helping them avoid serious financial losses or mismanagement of their affairs. This 55 year-old female caregiver described how her elder care lawyer informed her of the five-year rule, whereby any assets that were transferred fewer than five years prior to entering a nursing home could be used by Medicare to pay for a patient’s nursing home care or assisted living. The attorney advised her to transfer all funds and assets from her mother’s name into a trust. The participant explained that “if we hadn’t done that, where we are now, the sale of my mom’s house, all the proceeds [from] that would be gone, if we have to put her in assisted living now. So I mean, it was the best money we ever spent [on the attorney’s fees].” Another female caregiver, age 62 said that her elder care lawyer frequently sent out updates and e-mails with valuable information: “there’s some real issues in there that I think anybody in this situation that isn’t independently wealthy really needs to know. Because you can get screwed out of a lifetime of savings and be left [with nothing].” The same participant also made the point that elder care lawyers are often helpful because they are specialized and know the complications that accompany AD, as opposed to financial advisors who simply want to make money themselves through the sale of a product: “You’ve got to get somebody who’s specialized in this area. These financial advisors – it’s funny, somebody’s been calling me from [a financial services company], because we have an insurance policy with them. And they’re just too slick for me. They’re just – they’re looking for you to buy more of this and buy [...] and not that many people are knowledgeable in this area – in this particular disease.” This participant went on to say that “in the future, I’m sure that other financial advisors and other lawyers will have to become [more specialized in this area].” Such insights highlight caregivers’ desires to deal with professionals who are more knowledgeable and function as advisors or managers to help them navigate the complicated issues surrounding Alzheimer’s, planning, and care, rather than working with individuals whose primary focus may be on a product or service sale.

Discussion

Caregivers for a loved one with AD face a myriad of challenges balancing the physical, emotional and financial demands of providing care. While more research has been devoted to the physical and emotional stresses, these interviews highlight the concerns caregivers struggle with around financial matters. Although the sample of this study was limited in size, and only included residents of the metro-Boston area, and heavily favored female respondents, and may thus not be entirely generalizable to other populations, these interviews still provide insight into caregivers' priorities as they think about financially planning for the needs of a loved one with AD as well as for the needs of the rest of the family.

Participants reported that they wished they had done more in-depth planning for their loved one's financial incapacity, and most wished that they had saved more so that they would have more resources at their disposal. Planning for their loved one's care expenses was particularly important for caregivers, whether that involved saving for a nursing home, shifting assets to protect them and to enable their loved one to be eligible for care subsidies, or purchasing long-term care insurance earlier. They also advised other caregivers to seek out help and resources that might be available to them. Caregivers' thoughts about what they might have done differently, as well as their regrets about insufficient planning, underscore the stress and complexity of the financial issues surrounding AD. They also indicate a need among many caregivers for the information and advice that professionals may be equipped to provide.

Caregivers had somewhat mixed views about financial advisors as a source of professional advice on long-term financial and health care planning, but they were uniformly positive about elder care attorneys. Some participants were dubious about whether financial advisors simply wanted to sell them some kind of product and whether they knew enough about the disease itself to be helpful. Caregivers who had experience with elder care lawyers felt that their time and money had been well spent. They felt that these lawyers had protected their financial resources and been able to put their loved one's affairs in order effectively. In short, caregivers who used these professionals seemed to have a great deal of trust and confidence in them and the advice they offered.

The interviews also suggest, however, that there is a good deal of opportunity for professionals to advise caregivers on caring for a loved one with the disease and on the issues and stresses it raises. Caregivers consistently reported that they wished for additional support: in planning and organizing financial affairs for their loved one; in managing matters to protect resources for the loved one and for family; in securing resources to pay for health care-related costs; and in locating support resources. This suggests that professionals, whether they be financial advisors, family attorneys, accountants or geriatric care managers, may have to modify their approaches and expand their horizons if they are to be viewed as viable resources for caregivers of people with dementia. First, there is a need for professionals to know more about dementia and the issues associated with it, including the symptoms of the disease itself and warning signs of financial incapacity. In order to serve such clients and their families better, professionals need to be equipped with basic knowledge about how to order one's legal affairs, providing referrals to an elder care attorney or working in partnership with one as needed. Second, they will need to help clients to plan for the nature and costs of care. Ideally such long-term financial and health care planning will have taken place long before any signs of disease emerge, but for many families and situations, this will not be the case. Further, because the financial futures of others may be linked to the assets of the person with dementia, in planning for the patient's future, professionals may in fact also be planning for the family's future and in so doing, creating a client base for years to come. Finally, professionals from different disciplines may increasingly function as kinds of concierges for caregivers: in addition to providing advice around financial and legal matters, and in helping families to make plans for their financial future, they increasingly may be seen as a link to different available resources and information for caregivers.

While caregivers undoubtedly value these services that professionals provide, the overarching need to be able to trust them – to be confident that the professional is acting in the best interests of the care recipient and the family and not simply in their own best interest – is of paramount importance. One female spouse, age 62, said that the whole process of managing her loved

one's finances was "extremely, extremely [stressful]. Because I'm at the mercy of these professionals, that you pray that – you're trusting that they're honest." Establishing caregivers' trust and being armed with knowledge of the disease and the financial and legal challenges it raises will position professionals to provide better care for their clients and for their families and to help them navigate life with this complicated disease.

Implications for practice

1. For caregivers:
 - plan and save for dementia care costs;
 - familiarize themselves with the legal and administrative policies regarding dementia and estate planning;
 - investigate insurance plans and asset protection; and
 - consider using a financial or legal professional to assist with certain legal and financial aspects of caregiving.
2. For professionals:
 - familiarize themselves with dementia and the implication for individuals, families, and legal/financial planning;
 - work with families to plan ahead for dementia care; and
 - learn about resources available for caregivers and serve as a "conciierge" to help them take advantage of them.

References

- Alzheimer's Association (2014), "2014 Alzheimer's disease facts and figures", available at: www.alz.org/downloads/facts_figures_2014.pdf (accessed September 2015).
- Brown, J.R., Goda, G.S. and McGarry, K. (2012), "Long-term care insurance demand limited by beliefs about needs, concerns about insurers and care available from family", *Health Affairs*, Vol. 29 No. 1, pp. 102-8.
- Finkelstein, A. and McGarry, K. (2006), "Multiple dimensions of private information: evidence from the long-term care insurance market", *American Economic Review*, Vol. 96 No. 4, pp. 938-58.
- Förstl, H. and Kurz, A. (1999), "Clinical features of Alzheimer's disease", *European Archives of Psychiatry and Clinical Neuroscience*, Vol. 249 No. 6, pp. 288-90.
- Gamble, K.J., Boyle, P., Lei, Y. and Bennett, D. (2014), "The causes and consequences of financial fraud among older Americans", Center for Retirement Research at Boston College, CRR WP 2014-13, available at: http://crr.bc.edu/wp-content/uploads/2014/11/wp_2014-13.pdf
- Karttunen, K., Karppi, P., Hiltunen, A., Vanhanen, M., Välimäki, T., Martikainen, J., Valtonen, H., Sivenius, J., Soininen, H., Hartikainen, S., Suhonen, J., Pirttilä, T. and ALSOVA study group (2011), "Neuropsychiatric symptoms and quality of life in patients with very mild and mild Alzheimer's disease", *International Journal of Geriatric Psychiatry*, Vol. 26 No. 5, pp. 473-82.
- Kramer, B. (2014), "Dementia caregivers in Germany and their acceptance of new technologies for care: the information gap", *Public Policy Aging Report*, Vol. 24 No. 1, pp. 32-4.
- Marson, D. (2013), "Clinical and ethical aspects of financial capacity: a commentary", *American Journal of Geriatric Psychiatry*, Vol. 21 No. 4, pp. 382-90.
- The MetLife Mature Market Institute (2011), "The MetLife study of caregiving costs to working caregivers", available at: www.caregiving.org/wp-content/uploads/2011/06/mmi-caregiving-costs-working-caregivers.pdf (accessed September 2015).
- National Alliance for Caregiving and AARP (2009), "Caregiving in the US", available at: www.caregiving.org/data/caregivingusallagesexecsum.pdf (accessed September 2015).

National Alliance for Caregiving and Evercare (2007), "Evercare study of family caregivers-what they spend, what they sacrifice: the personal financial tool of caring for a loved one", available at: www.caregiving.org/data/Evercare_NAC_CaregiverCostStudyFINAL20111907.pdf (accessed September 2015).

Triebel, K.L. and Marson, D.C. (2012), "The warning signs of diminished capacity in older adults", *Generations*, Vol. 36 No. 2, pp. 39-45.

Widera, E., Steenpass, V., Marson, D. and Sudore, R. (2011), "Finances in the older patient: he didn't want me to take over", *Journal of the American Medical Association*, Vol. 305 No. 7, pp. 698-706.

Further reading

Jackson, S.L. and Hafemeister, T.L. (2010), "Financial abuse of elderly people vs other forms of elder abuse: assessing their dynamics, risk factors, and society's response", National Institute of Justice, US Department of Justice, Washington, DC, available at: www.ncjrs.gov/pdffiles1/nij/grants/233613.pdf (accessed September 2015).

Jackson, S.L. and Hafemeister, T.L. (2012), "Pure financial exploitation vs hybrid financial exploitation co-occurring with physical abuse and/or neglect of elderly persons", *Psychology of Violence*, Vol. 2 No. 3, pp. 285-96.

Kemp, B.J. and Mosqueda, L.A. (2005), "Elder financial abuse: an evaluation framework and supporting evidence", *Journal of the American Geriatric Society*, Vol. 53 No. 7, pp. 1123-7.

Torpy, J.M. (2011), "Cognitive impairment and money management", *Journal of the American Medical Association*, Vol. 305 No. 15, p. 1610.

Tueth, M.J. (2000), "Exposing financial exploitation of impaired elderly persons", *American Journal of Geriatric Psychiatry*, Vol. 8 No. 2, pp. 104-11.

Corresponding author

Olivia DaDalt can be contacted at: odadalt@mit.edu

For instructions on how to order reprints of this article, please visit our website:

www.emeraldgroupublishing.com/licensing/reprints.htm

Or contact us for further details: permissions@emeraldinsight.com